

Living Positively: The youth who will lead Africa out of the AIDS pandemic

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Grassroots



Josephine Nabukenya, Youth Programme Coordinator for MU-JHU Young Generation Alive, leading HIV awareness outreach for youth (Uganda). PHOTO: EMMANUEL MUSERUKA



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Community-based work, making all the difference for girls and young women

Powerful affirmation from the 22nd International AIDS Conference

Gender inequality has driven up HIV infection rates for girls and young women to alarmingly high levels. Across sub-Saharan Africa, three quarters of all the teenagers who now become infected with the virus are girls. That's the bad news. The good news is that people are finally starting to realize that community-based organizations (CBOs) hold the key to turning this unacceptable situation around.

The evidence came fast and furious this summer at the International AIDS Conference in Amsterdam. Expert after expert came forward to table studies and evaluations showing that the interventions community-based organizations have designed, and have been implementing for many years, are powerfully effective.

Irrefutable evidence now shows that certain types of support make a big difference:

- **Holistic programming** that looks at the situation of the *whole* person—and addresses all of the concrete challenges to well-being and gender inequality—brings down infection rates for teenage girls, and works to reduce gender-based violence.
- **Peer support groups for teens** are keeping girls and boys on the antiretroviral (ARV) treatment for HIV, promoting adherence, and keeping youth in programmes. They're also working to combat unequal gender norms.
- **Economic empowerment for caregivers** helps teens stay on treatment and in school, and avoid risky behaviour and unwanted pregnancies. Orphaned girls benefit the most. This just makes good sense—if the caregiver is cared for, the youth in their care are better provided for—emotionally and economically.
- **Community outreach, dialogue and education** work together to combat the stigma around HIV, and reduce violence against women and children.

The strongest message of all, coming from the International AIDS Conference in Amsterdam, is that it's time to stop focusing so single-mindedly on medical interventions. Holistic programming—addressing the whole person with a combination of psychosocial, medical, educational and economic support—is the way of the future. It's what will turn the tide for young women and girls in sub-Saharan Africa, and what will ensure that the global HIV&AIDS pandemic actually comes to an end.

The support that Conference experts called for is exactly the kind of support that African community-based organizations are delivering to the people in their communities, and we're sure that much of what they're recommending sounds quite familiar to *Grassroots* readers.

For far too long, the big players in the global HIV&AIDS response have been saying they can't fund community-based organizations because there isn't hard scientific proof that their programmes work. Well, that proof is now in, and there is very little time to waste. The challenge is urgent—to make the needed resources available, so community-based organizations can scale up their life-saving work! The lives of young, vibrant, hopeful girls and boys depend on it.

What follows is a conversation with just one of countless young people who are working with passion and determination to secure a safe, healthy and happy future for themselves and their peers.

Holistic programming is the way of the future. It's what will turn the tide for young women and girls in sub-Saharan Africa.

“You Have to be Living as an Example”

Living Positively—the youth who will lead Africa out of the AIDS pandemic

The SLF didn't wait to see “randomized cluster controlled trials” to start funding community-based organizations, and we don't need such expensive evidence to be convinced to redouble our efforts. All a person really needs to do is listen to community-based organizations when they talk about their work, and listen to the people whose lives have been transformed.

In this issue of *Grassroots*, we're sharing part of a conversation that Leah Teklemariam, SLF Director of Programmes, had with **Vivian Namara**, who is a youth peer counsellor with **Reach Out Mbuya (ROM)** in Uganda.

Vivian, you're one of the most powerful young women leaders at ROM—and before becoming a leader, you were a member of one of their peer support groups. What did ROM's support mean to you when you were a beneficiary of their programmes?

I joined ROM when I was 6 years old, when I was tested HIV positive in 2003. It was a really big deal for me, because without their support I just don't know if I could have taken it. I felt so lonely, I felt like I was the only person in the world who was HIV positive. But I got medication from ROM, counselling and educational support, and I joined their group for young children that met every



Vivian Namara PHOTO: ALEXIS MACDONALD/SLF

Saturday. Then I felt like, “Yes, at least I know there are other people who are positive like me and are my age!” I managed to gain more self-esteem. I met friends in the organization, and the doctors and counsellors were really close to me. I could open up and, with time, I grew to have this confidence I have now. I'm so proud to be part of ROM.

Every day I have to remind myself to take medication. I tell the young people in Friends Forum that maybe if we can all do this we will show the world that we are heroes.

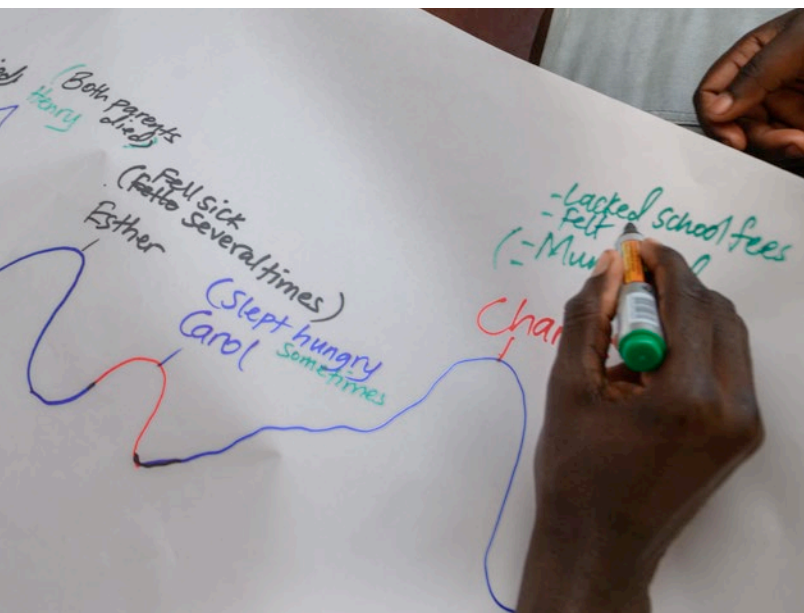
It's clear you've become a leader and an ambassador in your own right to the other young people in your community. What is your work now and what is your role with ROM?

My role in ROM is as a peer leader and peer supporter. ROM runs a group called "Friends Forum" where all young people living with HIV meet. We come together in the last week of the month, and talk about the challenges we face as young people in the community. Taking that medication is not easy. It's something no one wishes to do. Every day I have to remind myself to take medication. I tell the young people in Friends Forum that maybe if we can all do this we will show the world that we are heroes. We are heroes of our own lives, because it is very hard to accept your status, but if you do, then everything can start to change. ROM also runs a community sensitization programme. We go out into the community to sensitize them about HIV and about stigma, and once in a while we go on TV and radio shows, too.

I'm also a peer supporter at the adolescent clinic that ROM started. The youth were missing their appointments, and when they asked why, the children said, "Sometimes

there are elder people there, and we don't want them to see us, so it's better if we don't come. If we miss our medication for a week, well, someone might bring it to us..." ROM decided to set up a clinic just for adolescents. It's us, their peers. We are the ones doing the pill counting and weighing. We talk to them about their status and their health. This is more comfortable for young people. They come and they don't miss their appointments. When I was young, I was not comfortable with the adult counsellors. If I had a problem, I couldn't tell it to someone older than me. I was afraid she would scold me. This peer-to-peer counselling has really helped. When I talk to someone I'm also giving feedback to the counsellors. I can tell them that this youth needs help, she cannot come to you, but she needs help.

I am so proud that the children call me 'Mummy'. They all know where I am staying, and whenever they have a problem they come and let me know. They tease me saying, "Everyone calls you Mummy. You are getting old!" But I say, "I am fine with it!" It feels so nice, it is so good, to know that I am doing something to improve someone's life.



Above and right: MU-JHU Young Generation Alive activities encourage youth to share their personal stories and support each other (Uganda). PHOTOS: EMMANUEL MUSERUKA



When you think about your journey with the organization, and the programmes as they've evolved, what are the most important changes and successes you've seen?

I am happy to say that the viral loads amongst youth in the hospital are much lower now. Low viral loads are the sign that lets you know a person is taking their ARV medication regularly, and their health is improving. Before, it was too much. Each and every youth file had high viral loads recorded, and they were in counselling. The youth programmes have helped a lot. At least every week, 60% are improving, and if you ask them how they managed to get their viral loads down, they will tell you it is because of our programmes. If someone has a high viral load, we follow up on a peer-to-peer basis. No doctors, just us. So, that is how we've helped the youth adhere to their medication.

Also, we can see that the youth have really been motivated by some of us talking about our HIV status in public. They are wondering, where did we get the confidence to confront the world? I remember when I posted some pictures on Facebook a while ago, I had written "My status does not define me" and all my friends wrote back and told me "this is no good." I told them that it is good—that I am not afraid of stigma, and I am going to do this. I know someone is going to come and say, "Vivian, you helped me." I know someone, somewhere is going to say, "If she did it, I can do it."

Drawing on shared experiences to 'write the script', these girls are using role-play to support each other and educate their communities about the importance of girls' education. This scenario addresses the roadblocks they face in getting the education they know can help prevent abuse, early pregnancy and marriage, and high rates of HIV infection. Maasai Women Development Organization—MWEDO (Tanzania). PHOTO: ALEXIS MACDONALD/SLF

You can see that the children are freeing themselves from stigma and discrimination, no matter how the community sees them. They will get on their feet and walk. They are not going to stay down because of stigma. They have more confidence. And they know that when they join the programme, they might have a chance to work with the organization, so they work hard, and they really show you that they are working hard to be part of the organization—that is in their heads.

You have to be living as an example. If I am an ambassador, my viral load cannot be high, because the kids ask a lot of questions. Whenever I am home and I don't feel like taking my medicine, I am remembering what I am going to tell those kids: "When you have low self-esteem and stigma, you have to overcome it. You just say, 'this is my life, this is my medication—I am going to do this.' Today we are two, tomorrow we are three, the next day we are five! We are really doing something!"

How We Work

The Stephen Lewis Foundation's philosophy has always been firmly rooted in the notion that the expertise needed to turn the tide of HIV&AIDS in Africa is found at the community level, and that it is grassroots organizations that are keeping communities together, and resurrecting peoples' hopes and resilience.

We are driven entirely by the demands of these exceptionally effective grassroots organizations at the frontlines of the AIDS pandemic. There are no assumptions of Western hegemony, or top-down funding—we know that the communities are the experts on what they need, and what will, ultimately, defeat the pandemic. Our support, therefore, is structured to be quick, accountable (but not bureaucratic), flexible, holistic and sustained over the long term so that the organizations can have the certainty they need to carry out their work and expand its reach. We work with a women's rights, anti-colonial ethos, grounded in human rights and solidarity.

PARTNERSHIPS: We actively seek partnerships with groups that are of, by and for their communities, and include women and people living with HIV&AIDS on their boards and staff.

HOLISTIC APPROACH: Our partners know that the multiple traumas inflicted by the pandemic must be addressed together to rebuild lives, including physical, social, economic and emotional well-being.

DUE DILIGENCE FROM THE OUTSET: Before we decide to support an initiative, we visit every partner to evaluate its capacity, the strength of its connection to the community, and its accountability systems. We keep our overhead as low as possible, and our focus on the grassroots—hence our decision not to have offices in Africa. Our experienced field representatives regularly visit our partners for on-site monitoring and evaluation.

COLLABORATION: We maintain close contact with our partners, via regular communication and field visits, to facilitate relationships of trust and openness.

FLEXIBILITY AND CONTINUITY: There is no end yet to the pandemic, and the context continues to change. We accompany our partners as their work grows and deepens, and as they respond to new and emerging challenges.

Grandmothers to Grandmothers Campaign

The Grandmothers to Grandmothers Campaign was launched in response to the crisis faced by African grandmothers as they struggled to care for millions of children orphaned by AIDS. Since 2006, more than \$33 million has been raised! The Campaign has become a dynamic global movement driven by groups of grandmothers and *grandothers* in Canada, Australia, the UK and the USA. Through a variety of creative events, including concerts, Scrabble tournaments, selling jewelry and crafts, bike-a-thons, and garage sales, these groups work tirelessly to raise awareness and funds—with 90% of those funds sent directly to community-based organizations run by and for grandmothers raising orphaned children. Members of the Campaign know that when grandmothers are galvanized, nothing can stop them!

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Financial Overview 2017-2018

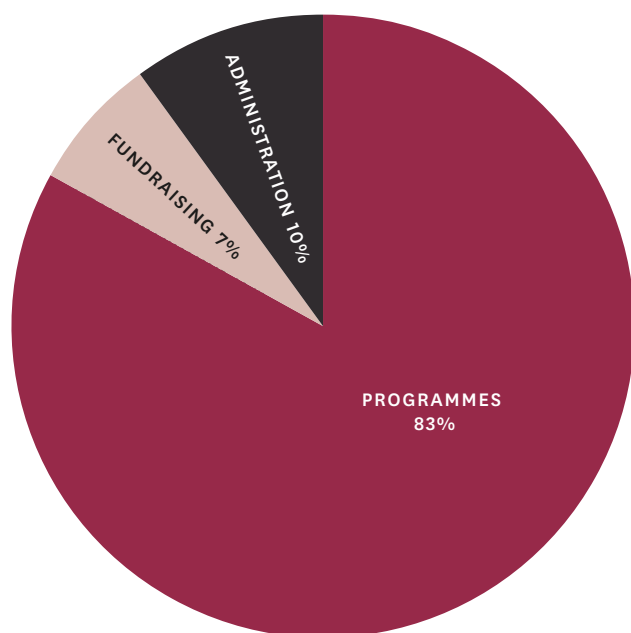
Programmes

We are deeply committed to getting the majority of our revenue to the community-based organizations with which we work. Between 2003 and June 2018 the Stephen Lewis Foundation disbursed and committed a cumulative \$114.3 million in programme spending, including direct support to over 1,700 initiatives with more than 325 community-based organizations in 15 African countries. This represents more than 83% of total expenditures over the past 15 years. To read more about our work with African partners, please visit: stephenlewisfoundation.org/what-we-do

Administration

Administration is essential to the success of every charitable organization. At the Stephen Lewis Foundation these are costs associated with day-to-day operations and expenditures that ensure we are accountable for how funds are being allocated. We are committed to keeping these administrative costs as low as possible through in-kind donations and pro bono support. We are proud to report that this year our administrative costs are 11% of our total revenue. For more information, please visit: stephenlewisfoundation.org/who-we-are/financials

WHERE YOUR MONEY GOES • 2003-2018



Between 2003 and June 2018, the SLF has committed and disbursed \$114.3 million to programmes, including direct support to over 1,700 initiatives with more than 325 CBOs in 15 sub-Saharan African countries.

Funds Development

In order to continue to support the innovative programming developed by our African partners, the Stephen Lewis Foundation has increased its fundraising capacity to engage supporters through a variety of recognizable initiatives, such as special events that feature the voices and work of our partners, and by encouraging critical monthly donations. This year we spent 11% of our revenue to support awareness-raising and fundraising.

Want More Information?

For a copy of the Foundation's full audited financial statements and the link to our annual Canada Revenue Agency (CRA) charity returns, please visit: stephenlewisfoundation.org/who-we-are/financials

The Foundation's fiscal year runs from July 1 to June 30. Our auditors are Grant Thornton LLP Chartered Accountants. The Foundation's charitable number is 89635 4008 RR0001.

If you have questions about our financial statements, please call 1-888-203-9990 ext. 244 to speak to Esther Vise, Director of Finance.

The holiday season is almost here, and our holiday tribute cards are now available!

Make your donation in lieu of a gift, and send a beautiful printed or electronic card to your family member, friend or colleague. We can send you one of our colourful tribute cards to personalize and deliver yourself, or we can mail it on your behalf. Or donate online and send an e-card for easy and immediate delivery. Strengthen the work of our grassroots partners by giving a gift that is truly meaningful!



Order your holiday cards today

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